

**TWO-YEAR REVIEW  
OF THE  
*PERSONAL DIRECTIVES ACT***

Submitted By:

Interdepartmental Coordinating Committee  
on Personal Directives

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**Alberta**  
GOVERNMENT OF ALBERTA

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The Committee would like to thank Regional Health Authorities, service providers, non-governmental organizations, and members of the public for sharing their experiences and views about the *Personal Directives Act*. The Interdepartmental Committee is also grateful for the insights provided by makers and agents.

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## EXECUTIVE SUMMARY

### PURPOSE

This report presents the findings of the evaluation of the *Personal Directives Act* over the two years following proclamation. The evaluation reflects the experience of makers [an individual who makes a personal directive], agents [an individual designated in a personal directive to make personal decisions on behalf of the maker], and service providers [such as Regional Health Authorities, acute and continuing care facilities, social agencies and organizations, and lawyers].

### BACKGROUND

The Alberta Government proclaimed the *Personal Directives Act* on December 1, 1997. The purpose of the *Personal Directives Act* (PDA) is to promote self-determination by enabling adult Albertans to appoint a substitute decision maker and provide instructions regarding personal non-financial matters in the event of future loss of capacity. This legislation is intended to respect individual autonomy and give individuals the opportunity to extend their right to self-determination over personal matters. Alberta Human Resources and Employment is responsible for administering the *Personal Directives Act* through the Office of the Public Guardian.

In anticipation of future periods of possible incapacity, an individual may name someone, called an agent, to make decisions about personal matters on his/her behalf. The individual may write instructions about personal matters, such as health care, participation in social activities, legal affairs, and place of residence. The legislation ensures that makers have a voice in the services and care they receive. The *Personal Directives Act* benefits adult Albertans who are capable of understanding the nature and consequences of a personal directive and want greater control over their future personal matters if they become incapacitated.

## CONCLUSIONS

Although it is early in the life of the legislation, the *Personal Directives Act* is serving its intended purpose. It is promoting self-determination by enabling adult Albertans to appoint a substitute decision maker and to provide instructions regarding personal matters in the event of future loss of capacity.

Most of the concerns expressed prior to proclamation of the *Personal Directives Act* have not materialized. One of the concerns expressed was the potential for family conflict. However, it is not the intent of the *Act* to resolve family disputes that arise when a personal directive is in effect.

For the vast majority of makers, writing a personal directive is straightforward. It provides an opportunity to discuss their wishes with family members before they become incapacitated. Using a standard form may inhibit this process. Although a personal directive may include any personal matter, the evaluation indicated that personal directives primarily include the following matters: 'health care', 'accommodation', and 'with whom the maker will live'. Significant discussion takes place between the makers and agents, resulting in a high degree of confidence on behalf of the agents that they know the makers' wishes and will be able to implement them.

In the next two years, the Government of Alberta should continue to:

- (1) inform Albertans about the *Personal Directives Act*;
- (2) educate service providers about their responsibilities under the *Personal Directives Act*;
- (3) provide information to professional organizations and groups about the importance of developing policies and protocols respecting implementation of the *Personal Directives Act*;
- (4) gather information about the ongoing performance of the *Act*, including court challenges.

In addition, the Government of Alberta should conduct a review of the *Personal Directives Act*, and examine the three pieces of legislation concerning substitute decision making (the *Dependent Adults Act*, the *Powers of Attorney Act*, and the *Personal Directives Act*) to ensure consistency and clarity.

## 1.0 PURPOSE

The Alberta Government proclaimed the *Personal Directives Act* on December 1, 1997. The Government decided to monitor and evaluate the implementation of the *Act* over the two years following proclamation, and to report the findings to the Legislature.

This report presents the findings of the evaluation of the *Personal Directives Act* over the two years following proclamation. As it is early in the life of the legislation, we are aware of only a small number of personal directives that have been brought into effect.

The evaluation reflects the experience of makers [an individual who makes a personal directive], agents [an individual designated in a personal directive to make personal decisions on behalf of the maker], and service providers [such as Regional Health Authorities, acute and continuing care facilities, social agencies and organizations, and lawyers].

## 2.0 BACKGROUND TO THE PERSONAL DIRECTIVES ACT

The *Personal Directives Act* is the culmination of years of research and interest in substitute decision making. Following the recommendations of the Rainbow Report (1989), the Alberta Law Reform Institute released the first of two reports in 1991, Advanced Directives and Substitute Decision Making in Personal Health Care. After considerable consultation across the province, another report with the same name was released in March 1993. This was a joint report of the Alberta Law Reform Institute and The Health Law Institute. This second report contained draft legislation called the Health Care Instructions Act. This proposed legislation extended beyond health issues and included nutrition, personal hygiene and choice of residence.

At the same time, the Office of the Public Guardian was designing amendments to the *Dependent Adults Act* to allow competent adults to essentially make their own guardianship arrangements. The documents were proposed to be called, "Representative Agreements".

In November 1994, the Government of Alberta proposed a bill addressing personal directives in response to extensive public consultations with Albertans, and court decisions in other jurisdictions. The consultations revealed that

individual Albertans want to take greater control of decisions affecting personal matters, should the time ever come when they are not capable of making those decisions themselves.

On April 4, 1996 Carol Haley—MLA, introduced the *Personal Directives Act*, and the Act received royal assent the following month. The Government of Alberta established an Interdepartmental Coordinating Committee on Personal Directives—consisting of Health [now Health and Wellness], Community Development, Family and Social Services [now Human Resources and Employment], and Justice—to facilitate the implementation of the *Personal Directives Act* and to monitor its effectiveness over the two years following proclamation in December 1997.

The purpose of the *Personal Directives Act* (PDA) is to promote self-determination by enabling adult Albertans to appoint a substitute decision maker and provide instructions regarding personal non-financial matters in the event of future loss of capacity. This legislation is intended to respect individual autonomy and give individuals the opportunity to extend their right to self-determination over personal matters. Alberta Human Resources and Employment is responsible for administering the *Personal Directives Act* through the Office of the Public Guardian.

In anticipation of future periods of possible incapacity, an individual may name someone, called an agent, to make decisions about personal matters on his/her behalf. The individual may write instructions about personal matters, such as health care, participation in social activities, legal affairs, and place of residence. The legislation ensures that makers have a voice in the services and care they receive.

The *Personal Directives Act* benefits adult Albertans who are capable of understanding the nature and consequences of a personal directive and want greater control over their future personal matters if they become incapacitated. Families and friends know that decisions made will be based on the individual's instructions and/or beliefs, wishes and values. Service providers can rely on an agent (if one is named) to make decisions on the individual's behalf and, if an agent is not named, can follow the individual's clear and relevant instructions.

### **3.0 ISSUES ARISING PRIOR TO PROCLAMATION OF THE PERSONAL DIRECTIVES ACT**

During debate of the proposed *Personal Directives Act*, Members of the Legislative Assembly identified several key issues and were concerned that the proposed legislation seemed to:

- provide an opportunity for assisted suicide and non-voluntary euthanasia;
- exclude a maker's family (spouse and children) in the process of preparing the personal directive;
- rely solely on a maker's knowledge of current medical science and technology, rather than ensuring the maker obtained medical advice when preparing a personal directive;
- restrict the ability to revoke the personal directive if the maker is incapacitated;
- negatively affect the organ donor program; and
- allow an agent to use confidential personal information and records respecting the maker for purposes other than those that are relevant to the personal decision to be made or the determination of the maker's capacity.

Prior to proclamation of the *Personal Directives Act*, the Minister of Health received letters in a write-in campaign outlining some Albertans' fears that completing a personal directive equates to:

- denying God's power to give and to reclaim human life on His terms;
- denying the sanctity of human life in our hospitals, nursing homes and other health-care facilities;
- protecting doctors and health care providers from lawsuits resulting from their actions in terminating patients' lives;
- protecting the claims of beneficiaries to the proceeds of insurance policies of patients whose lives they have the power to end;
- legalizing passive euthanasia in Alberta;
- allowing patients who are unable to communicate their wishes to be legally starved to death by a health care provider;
- preventing the maker of a personal directive from receiving palliative care if necessary.

Letters and submissions from Albertans prior to proclamation of the *Personal Directives Act* indicated that the general public seemed to be misinformed in the following areas:

- details of implementation of a personal directive (how to determine whether a maker lacks capacity, and the responsibilities of service providers when a personal directive is in effect);
- whether or not legal advice is required to write a personal directive;
- whether or not a person needs to appoint a guardian when writing a personal directive; and
- the relationship between the *Personal Directives Act* and other pieces of legislation.

In addition, specific groups within the medical community expressed concern that the *Personal Directives Act* would limit or impede their professional practice, such as research in intensive care units and organ donations. Moreover, some owners/operators of continuing care facilities did *not* understand that writing a personal directive *must not* be a requirement for a person obtaining residential accommodation or for continued residence in residential accommodation.

#### **4.0 ACTIONS TAKEN TO INFORM ALBERTANS ABOUT THE PERSONAL DIRECTIVES ACT**

During debate of the proposed *Personal Directives Act*, Members of the Legislative Assembly encouraged the Government of Alberta to make sure that the education and communication is clear respecting the responsibilities of the maker, agent, and service providers. The Government of Alberta took several steps to make Albertans aware of the *Personal Directives Act*.

##### **4.1 Development and Distribution of Educational Materials**

The Interdepartmental Coordinating Committee oversaw the development and focus testing of specific educational materials designed to clearly communicate the respective responsibilities of the maker, agent, and service providers. Alberta Health and Wellness, in conjunction with Alberta Community Development, Alberta Justice, and Alberta Human Resources and Employment, developed a brochure and three booklets to communicate information about the *Personal Directives Act*. One booklet discussed the process of writing a

personal directive, another explained the responsibilities of service providers under the Act, and a third outlined the duties and obligations of an agent.

With the assistance of facilitators from Alberta Community Development, nine focus groups were conducted across the Province which included service providers, the general public, and seniors. The participants stated the booklets were: (1) written in plain language; (2) easy to understand; and (3) useful.

The Interdepartmental Coordinating Committee revised the educational materials based on comments from the focus testing sessions. Approximately 300,000 booklets and 500,000 brochures were printed and distributed.

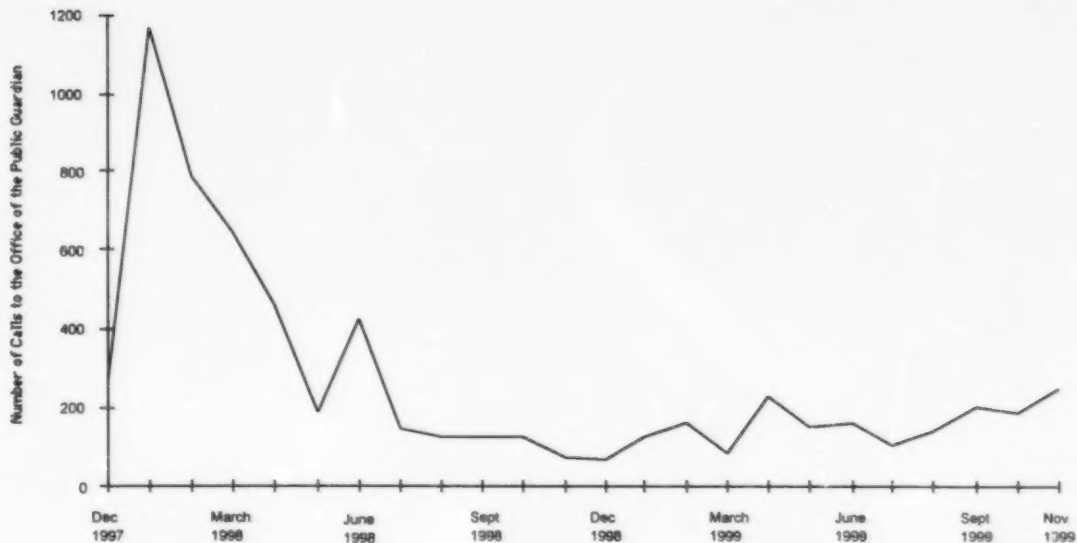
#### **4.2 Telephone Inquiries About the Personal Directives Act**

In December 1997, the Office of the Public Guardian established a provincial toll-free telephone line, and engaged two staff to handle incoming calls. After six months, an 'electronic call processing' system was established.

Approximately 6,400 people called the toll-free line during the two years following proclamation of the *Personal Directives Act*. According to Exhibit 1, the highest number of calls occurred during the first few months after proclamation of the legislation. Exhibit 1 also illustrates that since December 1998, there has been a continued escalation in requests for information about the *Personal Directives Act*, and this is unlikely to change for the next few years.

## EXHIBIT 1

### NUMBER OF CALLS TO THE OFFICE OF THE PUBLIC GUARDIAN RESPECTING THE PERSONAL DIRECTIVES ACT



#### 4.3 Presentations by Government Departments Respecting the Personal Directives Act

To ensure people understand the responsibilities of the maker, agent, and service providers, Alberta Health and Wellness made 120 presentations respecting the *Personal Directives Act*. Since proclamation, the Office of the Public Guardian has made more than 500 presentations to a variety of audiences, including financial planners, college students and faculty, seniors, and church groups.

The presentations have been effective in helping people to think about making a personal directive. For example, some of the participants stated:

- "you really have to think about your life and how you want to live it if you lose capacity";
- "putting your wishes in writing is important";
- "the personal directive can be simple and I don't need to write 18 pages of instructions";
- "I can select my caregivers and agents before something happens to me";

- "I now understand the difference between guardianship and appointing my own agent";
- "it is important to be careful in the wording—'heroic measures' doesn't really say anything, be blunt and direct and to name who I want to represent my interests"; and
- "I can include things in the personal directive that I don't want to happen to me—e.g., if I lose capacity I don't want to be taken to smoky bingo halls for a day of recreation because I don't like to be around smokers today".

#### 4.4 Activities by Non-Government Agencies Respecting the Personal Directives Act

The Provincial Health Ethics Network (PHEN) has also made presentations to various stakeholders respecting the *Personal Directives Act*. Specifically PHEN made 34 presentations between November 1997 and January 1999 [22 to the public, and 12 to organizations]. PHEN also published a handbook entitled Preserving Dignity: Personal Directives, which provides a detailed explanation of various sections of the *Personal Directives Act*, particularly as they pertain to decision making in health care.

In another initiative undertaken between November 1998 and February 1999, the Provincial Health Ethics Network collaborated with the Office of the Public Guardian to jointly host seven discussion sessions throughout Alberta, marking the first anniversary of the *Personal Directives Act*. The sessions were open to all interested personal care providers, administrators, organizational representatives, and members of the public. The primary purpose of the sessions was to hear from care providers and other Albertans experienced in matters related to personal directives and familiar with associated concerns and difficulties. These facilitated forums stimulated dialogue about the effect the legislation had on the provision of care, and the ethical issues related to the provision of service to those who lack capacity or are at risk of loss of capacity.

The Office of the Public Guardian and the Provincial Health Ethics Network jointly released a report entitled, Personal Directives: A Retrospective on Year One and the document presents some of the challenges noted by session participants, most of whom were service providers.

The report prepared by the Office of the Public Guardian and the Provincial Health Ethics Network also pointed out that "personal directives were perceived

as having both a positive and negative impact on the delivery of health care. Health care communication was *facilitated* if people were well prepared and personal directives were clear. However, communication was *hindered* if people were ill advised, or if the personal directives and agents were not available."

The Provincial Health Ethics Network maintains a web site which provides information to the general public, Regional Health Authorities, and service providers. The web site includes information about writing a personal directive, sample forms for appointing an agent and stating instructions, and a list of resources such as videos.

In October 1997, the Legal Education Society of Alberta delivered two seminars respecting the *Personal Directives Act*. Physicians and lawyers attended the seminars that were held in Calgary [156 participants] and Edmonton [152 participants]. In addition, the Legal Education Society of Alberta conducted two seminars in October 1998—one in Calgary and the other in Edmonton, and devoted a 'section' to presenting information about the *Personal Directives Act*. The Law Society of Alberta has also published articles respecting the *Personal Directives Act* in its newsletter.

## 5.0 EXPERIENCE OF MAKERS AND AGENTS

Since a personal directive is a very private matter, there is no way to identify how many people have prepared one. In this review, only a few makers and agents agreed to provide information about their experiences in preparing a personal directive and bringing it into effect.

Most of the makers indicated the personal directive ensures their families know their wishes. This provides the maker with a "feeling of control" and "peace of mind", and it also alleviates a burden for the family because they will know what to do if the maker becomes incapacitated.

Makers perceive it is very easy to prepare a personal directive and, both makers and agents believe it provides peace of mind for all parties. The directive is also seen as an effective vehicle to assist the maker in communicating his/her wishes, beliefs and values to service providers—particularly with respect to 'health care', 'accommodation', and 'with whom the maker will live'.

Most of the makers received help from someone when preparing their personal directive—such as an Office of the Public Guardian Regional Representative, an adult child, a lawyer, or a friend. Some of the makers used a form to assist them in writing the personal directive, and all of the makers stated they found it easy to write their personal directive.

Of the makers who were interviewed during this review, the majority had 'named an agent'. In fact, most of these makers had 'named multiple agents'—usually the spouse and adult children, or adult children and another relative. Most of the makers stated they have spent several months discussing their wishes with the agent to assist this individual in making decisions that are consistent with the maker's values and beliefs. Moreover, the makers have provided a copy of their personal directives to their agents.

'Health care', 'accommodation', and 'with whom the maker will live' are the matters most frequently included in personal directives, while 'participation in employment activities and educational activities' are matters included less frequently in the directives. Some makers also included 'other' matters, such as 'being close to pets', and further comments about resuscitation.

Since a personal directive is a very private matter, there is no way to identify how many people have been named as agents. The agents who were interviewed during this review described their role in the following ways:

- "when the maker is no longer capable of making decisions, I would take over to decide what is best for the maker";
- "my role is to make choices for the maker when the maker can no longer make choices";
- "my role is to carry out the maker's wishes and to ensure that nobody interferes with that role"; and
- "if my parent is in the hospital then I will work with the doctor to decide how far to go—i.e., to keep my parent as pain free as possible, and to decide whether my parent should be resuscitated".

## **6.0 EXPERIENCE OF SERVICE PROVIDERS**

It is difficult to identify service providers who have experience with substitute decision making under the *Personal Directives Act*. However, some service providers from acute care and continuing care facilities have had direct

experience in bringing a personal directive into effect. These staff noted it is a policy of their facility to ask people, on admission, if they have a directive. The personal directive is placed on the resident/patient's chart for easy access.

The service providers indicated the personal directive listed at least one agent, and in each case it was 'very easy' to contact the agent. Most of the agents were 'very willing' to make decisions on behalf of the maker of the personal directive.

Service providers noted the following examples of situations in which they contacted an agent concerning a personal directive prepared by one of their residents/patients:

1. In one situation, the individual had been admitted to an acute care facility but did not have a personal directive. After being discharged from hospital, the individual prepared a directive. A few weeks later, the person was re-admitted to hospital and had brought his personal directive. On re-admission the individual seemed to be confused and was unable to complete the form to consent to a CAT scan. Upon re-admission, hospital staff examined the personal directive to locate the name and phone number of the agent. The agent was contacted and together with a physician, determined the patient had lost capacity to make decisions. The agent completed the consent form for the CAT scan, and the test was conducted by the hospital.
2. In a different situation, a resident being admitted to a continuing care centre appeared confused. The individual did have a personal directive. The facility manager contacted the individual's physician, the agent (a family member), and other members of the family. However, it took approximately 10 days to locate the agent because the individual was away on holidays. The agent consulted with the physician to assess capacity, and they declared that the person had lost capacity to make decisions.

Once the loss of capacity had been declared, the facility requested the agent to make specific decisions about the care of the individual, particularly with respect to restraining the resident to prevent her from falling. During the discussion the facility informed the agent that the resident had a tendency to fall out of chairs, and requested permission from the agent to restrain the resident in certain situations to ensure her safety from falling. The agent decided not to permit the facility to restrain

the resident and the next day the individual fell and broke her hip. The agent made the decision permitting surgery for the resident. Unfortunately, the resident died three days after surgery.

After the death of the resident, the family exhibited a lot of guilt and met on several occasions with the facility manager. During these discussions, the family said they felt a lot of pressure which they really did not want to assume—they really wanted the professional staff at the facility to make the decisions.

Some of the Regional Health Authorities experience situations related to 'do not resuscitate' [DNR] orders on personal directives. One Regional Health Authority explained that when the directive lists an agent, as well as a DNR order, this creates complications for acute care facilities. For example, hospital staff are uncertain how to handle the situation in which a patient—who has a personal directive—is in an operating room where he/she has a negative reaction to the anaesthetic and needs to be resuscitated. That is, staff are unsure whether they should resuscitate the individual and then contact the agent, or whether they should follow the personal directive, and not resuscitate, even if resuscitating the patient will save the individual with *no adverse physical effects*.

The same Regional Health Authority noted that some mental health patients who have attempted suicide come to the hospital with a personal directive which includes a 'do not resuscitate order'. Under these circumstances, some hospital staff are uncertain what actions to take.

Service providers want more information and/or need to seek legal advice about the following issues: (1) assessing capacity for each decision; (2) providing emergency medical service when the individual has a personal directive; and (3) taking actions to provide service when there are no clear directions in the personal directive, or when there is a conflict between the agent and the service provider.

## 7.0 CONCLUSIONS

Although it is early in the life of the legislation, the *Personal Directives Act* is serving its intended purpose. It is promoting self-determination by enabling adult Albertans to appoint a substitute decision maker and to provide instructions regarding personal matters in the event of future loss of capacity.

Most of the concerns expressed prior to proclamation of the *Personal Directives Act* have not materialized. One of the concerns expressed was the potential for family conflict. However, it is not the intent of the *Act* to resolve family disputes that arise when a personal directive is in effect.

For the vast majority of makers, writing a personal directive is straightforward. It provides an opportunity to discuss their wishes with family members before they become incapacitated. Using a standard form may inhibit this process. Although a personal directive may include any personal matter, the evaluation indicated that personal directives primarily include the following matters: 'health care', 'accommodation', and 'with whom the maker will live'. Significant discussion takes place between the makers and agents, resulting in a high degree of confidence on behalf of the agents that they know the makers' wishes and will be able to implement them.

## 8.0 NEXT STEPS

In the next two years, the Government of Alberta should continue to:

- (1) inform Albertans about the *Personal Directives Act*;
- (2) educate service providers about their responsibilities under the *Personal Directives Act*;
- (3) provide information to professional organizations and groups about the importance of developing policies and protocols respecting implementation of the *Personal Directives Act*;
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In addition, the Government of Alberta should conduct a review of the *Personal Directives Act*, and examine the three pieces of legislation concerning substitute decision making (the *Dependent Adults Act*, the *Powers of Attorney Act*, and the *Personal Directives Act*) to ensure consistency and clarity.